

Developmental Disabilities Council
Meeting minutes
Wednesday, January 11, 2017
Margaret M. O'Neill Building, Dover, DE
Division of Vocational Rehabilitation, Pencader Corporate Center, Newark,
DE

Members Present: Barbara Monaghan (Chairperson), Carol Barnett, Alex Eldreth, Alvin Emory Jr., Terri Hancharick, Brian Hartman, Esq., Katie Howe, Nancy Lemus, HarrietAnn Litwin, Katie Macklin, Debra McCann, Karen McGloughlin, Beth Mineo, Shawn Rohe

Members Absent: Maitri Campbell, Angie Ehst, Karen Gallagher, Lillian Gibbons, Laura Greene, Michael Harris, Rick Kosmalski, Daniese McMullin-Powell, Carrie Melchisky, Joseph Merritt, Jr., Angela Mitchell, Sue Ellen Powell, Jill Scannell, Steve Slotkin, Steven Yeatman

Staff Present: Pat Maichle, Kristin Cosden Harvey, Stefanie Lancaster, Emmanuel Jenkins (absent)

Guests: Victoria Counihan, Libby Cusack, Bill Monaghan, Diann Jones, Kandi Pickard (NDSS), Colleen Hatcher (NDSS), Sara Hart Weir (NDSS)

- I. Call to Order** – Barbara Monaghan called the meeting to order at 9:37 a.m.
- II. Approval of Minutes** – Brian Hartman made the motion to approve the minutes as submitted. Karen McGloughlin seconded. The minutes were approved by Council.
- III. Approval of Agenda** – The request was made to move Sara Weir's presentation up to right after Current Business. With this change, Brian Hartman made the motion to approve the agenda as submitted. Karen McGloughlin seconded. The agenda was approved by Council.
- IV. 5 Minute Public Comment Period** – The following were comments made:
 - Terri Hancharick stated that nationally over 500 people are murdered by parents or caregivers. On March 1st there will be a gathering to remember those that have died. A day to commemorate and remembers those people with disabilities whose lives were lost.
 - Diann Jones stated that she as well as Jamie Wolfe and Barbara Monaghan have been meeting to discuss starting a group called DANCE. This group is a support group for people with disabilities who have been diagnosed with cancer to help provide support and suggestions for resources for them.in.
 - Beth Mineo stated that the Center for Disabilities Studies has received a grant for Home Automation and Renovations. Applications for individuals to apply for these grant funds are currently available on CDS's website.

- Nancy Lemus discussed concerns she had regarding licensing requirements for home health agencies being covered county to county. This topic is being discussed and addressed in collaboration with the State Council for Persons with Disabilities (SCPD) and AARP.

V. Chair's Report – Barbara stated that the Supported Decision Making workgroup has met for four months and recommendations have now been sent to the Secretary of Division of Health and Social Services (DHSS). The presentation for the LIFE Conference is ready.

VI. Staff Report – Pat stated the following:

- a) Pat introduces the DD Council's current interns - Carmen Watson and Nicole Johnson from Del Tech. They will be assisting with the Disability history project. They will be going to Archives to do more research for this project.
- b) Pat has been asked to serve on the National Advisory Group for the grant to enhance and expand the Partners in Policymaking advocacy training program. There will be a webinar for this on January 17th. A lot of the work that will be done will be via electronic process but will have an in person meeting in Washington at a later date.
- c) The Public Policy seminar will be held on March 20-22nd in Washington DC. This is a collaborative disability seminar in Washington. A meeting will try to be scheduled with our congressional folks to discuss important issues the Council feels should worked on at a federal level. Let Pat know soon if you want to attend.
- d) Governor Elect Carney has begun to choose his department nominees. There have been a number of nominees sent to the media. Hopefully we can work with them on our issues. The Secretary of Safety and Homeland Security has not yet been chosen. As we know, we will let you know.
- e) There will be a webinar held on January 12th at 2:30 p.m. hosted by the by FEMA. People with disabilities have not been involved in many of these discussions for active shooter awareness guidance. If interested in this topic, please register online at www.adapresentations.org/registration/php.
- f) The Inclusion Conference will be held on March 15th at Dover Downs. If you are interested in DDC covering your cost, let Stefanie know, as the DDC will pay for the registration fee if you are a DDC member.
- g) The Junior Partners in Policymaking deadline for applications to be submitted has been extended to February 28th. This program is for individuals ages 15-22 with or without disability. The program will be held at Delaware State University from June 16-23rd.

VII. Financial Report

Financial Advisory Committee Report – A copy of the report was provided in the packets to each member. There are no real updates to report at this time. There is currently approximately \$47,000 left to be obligated in FY2016 funds and \$101,000 in FY2017 funds. Please continue to think of projects to get these 2016 grant funds obligated before September 2017.

VIII. Current Business

1. Legislative Update – Pat reported the following:

- a. A copy of the Legislative Policy Agenda was provided to those in attendance. These items listed were the top ten items that the collaborative meeting developed and will be shared with legislators. A copy of this document will also be handed out at the LIFE Conference as well.
 - b. The Supreme Court hearing case on IDEA and IEP's in schools. This is being called FAPE – the Free Appropriate Public Education case which will be heard soon. Brian Hartman stated that Delaware is more progressive with this as Attorney General Matt Denn has helped with this. The Supreme Court has not addressed this issue since 1982.
 - c. Representative Heffernan introduced the Organ Transplant bill regarding non-discrimination and access to organs for people with disabilities. This will be heard in committee this week. All advocacy organizations have been at Legislative Hall to present testimony. People with disabilities are currently being kept off organ transplant lists by medical professionals due to the belief that some individuals with disabilities may not be able to care for their bodies the way they need to for the bodies to accept these transplants.
 - d. An Accessible parking bill will be reintroduced during this legislative session.
 - e. Nurse Delegation discussions will begin today with AARP at 3pm for those who receive services in their own home.
 - f. An Assisted Suicide/Death with Dignity bill will be reintroduced.
 - g. A Motorcycle Helmet bill has been introduced.
 - h. HB17 regarding school attendance is a bill that wants to raise attendance age that allows kids to leave school without parental consent.
2. **LIFE Conference** – Save the Date cards were distributed. If any member wishes to attend, please let Stefanie know so that she can register you as the DD Council pays for its members to attend.
 3. **Self-Advocacy** – Delaware People first is hosting a Self-Advocacy Conference that will be held on May 20th at Dover Downs. The details of the conference are still being developed. More information will be shared as it becomes available.
 4. **Administrative Changes in Government** - Pat discussed this earlier in the agenda. As more information is available it will be shared with Council.

IX. Committee Reports

1. **Adult Issues** – Terri Hancharick acknowledged the passing of Larry Henderson's. The Committee wants to carry on his torch that he had started as a member of DD Council. The Committee is currently working on a request for proposals for the sexual health objective.
2. **Children and Families** – Alex Eldreth stated that the Committee has been struggling working on four objectives as some of them must be worked on concurrently. The Director of the Division of Medicaid and Medical Assistance came to discuss the nutrition and exercise goals. It was discussed to offer free or low cost programs to those

with disabilities. Alex also stated that the Committee is in need of additional members. If any member is currently not on a Committee, as it is a requirement of a Member on the Council, please join us at our next meeting on February 20th at 1:30pm at the Division of Developmental Disabilities Services (DDDS) office in Bear.

3. Policy and Law

a. Supported Decision-Making – Rick Kosmalski was not present so Terri Hancharick reported on his behalf. The Supported Decision Making workgroup has submitted their final report with recommendations on how to implement this new option for individuals in Delaware. The final report was submitted to Secretary Landgraf and will be sent to the new Secretary when that person begins work.

4. Membership – Karen McGloughlin presented a plaque to Diann Jones on behalf of Karen Gallagher in recognition for her 12 years of service as a Member of the DD Council. Diann stated she joined the Council the year she graduated from the Partners in Policymaking program. She stated it has been an honor to be a part of the Council. She has learned so much from it, especially how to be her own advocate. Had she not been part of the Council or Partners graduate, she doesn't know where she would be. Diann hopes that after her taking a year's rotation off of Council that her health will be better and she can reapply.

Karen McGloughlin also reported that there will be a New Member Orientation and Ethics training that will be held on February 10th in the DDC office, Margaret O'Neill Building, 2nd floor conference room. Please let Stefanie know if you plan to attend.

Pat stated that Alvin Emory has notified the Council that he will be returning early from his medical leave of absence.

5. Consumer Caucus – Joey Merritt was not present at the meeting but Pat stated the next meeting will be held on February 11th at 9:30 a.m. at the ChesDel Restaurant. Please let DDC staff know if you plan to attend.

6. Partners Oversight – Kristin Cosden Harvey talked about Junior Partners in Policymaking Program earlier in the agenda. Karen McGloughlin did not have anything else to add at this time.

X. New Business

1. Sara Weir, NDSS – ABLE Act (moved up in the agenda to before current business) – Sara Weir from the National Downs Syndrome Society presented information to the Council regarding NDSS and ABLE accounts. Sara stated that the National Down Syndrome Society was founded in 1979. Their headquarters is located in New York with their national office in DC.

An ABLE account is an account that individuals with disabilities may set up to save money in a tax-exempt account that may be used for qualified disability expenses while still keeping their eligibility for federal public benefits. 85% of

Congress supported the ABLE Act. ABLE is one of the most significant pieces of disability legislation since the Americans with Disabilities Act which passed 25 years ago.

ABLE Accounts became a reality in June 2016, when Ohio became the first state to launch its program. Currently 10 states have ABLE programs: OH, NE, TN, FL, MI, OR, KY, VA, AK RI). Recently, federal statutes changed allowing individuals in DE to open an account in any state other than FL.

Sara provided information regarding eligibility requirements, impact on Federal Benefits such as SSI and Medicaid, the difference between a 529 account and an ABLE Account, and a Special Needs Trust vs. ABLE Account.

Handouts provided today are available as requested. For more information, please contact Sara directly at sweir@ndss.org or visit any of the following websites for additional information:

<http://www.ndss.org/able>
<http://www.ndss.org/ableprograms>
<http://www.ndss.org/Global/Policy/ABLE/ABLE-Anniversary-Report-online.pdf>

2. JFC Hearings – Pat stated a JFC hearing schedule is currently not available. As soon as it is posted, she will share with the Council. The schedule can also be viewed on www.legis.delaware.gov.

3. Future Speakers – Upcoming speakers are as follows:

- i. March – Laura Strmel will come to speak about how organizations can change their business practices to better serve those who want to go to work. We will also have Carmen Watson and Nicole Johnson, DDC’s current interns, present information that they have gathered thus far doing research for the Disability History Project.
- ii. May - Cheryl Bates Harris will discuss the “Bottom Dollar” video that was produced by The National Disability Rights Network (NDRN).
- iii. July – Lanny Edelson with the Families Speaking Up group will come to discuss segregated settings and share their views with the Council.
- iv. September - Brian Freedman from CDS will come to discuss work they are doing on autism.

XI. Other Council Business – No other business to discuss at this time.

XII. Adjournment – The meeting was adjourned at 11:25 a.m.

